

Activities for Children with Sickle Cell Disease



California Department
of Health Services
Genetic Disease Branch
Newborn Screening Program

Most children with sickle cell disease can look forward to a full life. It is important that they be prepared for adulthood and living on their own. School, friends, hobbies and work are all part of helping them grow up.

The outlook for people with sickle cell disease gets better every year.

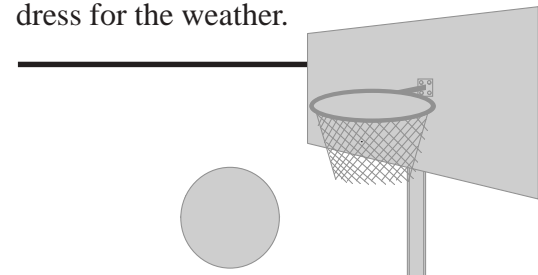
Here are a few tips to help children with sickle cell disease to be better able to enjoy a full life.

Self-Esteem

School Sports: for Boys and Girls

One of the ways that many children build self-esteem is through sports. If they want to play school sports, help them to be realistic about what they can do. Look at their strengths and find a sport that matches these.

If the sports program has a leader or coach, tell them about the child's special needs. Remind the child of the need to: drink when thirsty, rest when tired, and dress for the weather.



Help the child feel good about himself. Pay attention to more than just the problem. Notice skills, strengths, interests and style.

Praise children when they do well

You can't give too much praise. Children thrive when they are told that they are special. They feel good when someone sees something they've done well.

Listen to what children have to say

Ask the child questions. Show him that you care about what he thinks and feels.

Help them get involved in things besides their illness

Children can try some of these things to see if they want to do them:

- ★ Playing music, or singing
- ★ Being with friends
- ★ Learning the computer
- ★ Drawing or working with clay
- ★ Playing chess or other board games
- ★ Acting in a play
- ★ Reading books



Be careful not to push the child to compete where he can't succeed. If he can't run very long without getting sore or tired, don't force him to play fast sports. Help him to find at least one thing he can do well and enjoy.



Accepting themselves

When the child starts school, she may begin to notice that she is different from other children. When the child becomes aware of having "a disease" she may feel afraid or angry. The child may think that she got sick because she did something wrong.

Make sure the child knows that she didn't get the disease because they were "bad". Nothing the child did gave her the disease. Nothing she can do will get rid of it.

The child needs to accept the fact that he has sickle cell disease and make the most of his life. Tell him that except for having the disease, he is just like other children. Help the child to learn what he can and cannot do so he can gain more control.

Fitting in

We all like to feel that we belong. The child with sickle cell disease may be afraid that she won't fit in because the disease makes her different. She may think that others will make fun of her or treat her "special".

Some children feel good about telling their friends about sickle cell disease. Others don't want anyone to know. It is good for children to tell at least one close friend about his disease. If no one knows, it is more likely that the child will feel ashamed of his secret. When friends know, they can support the child when he needs it.

If the child doesn't know what to say to her friends, let them practice with you first. Their friends will handle it best if she tells them what the disease means and that they can't catch it. Once she has told others, she will probably feel better about herself.

Especially for parents

Children with sickle cell disease can learn to take care of themselves, even though they have the disease. They need to do things on their own. You still have to see that your child gets what she needs. But your job as parent is changing. You need to help the child learn to do things for herself.

By age 6, most children want to start doing things themselves. Your child may want to:

- ★ Help make his own breakfast or lunch.
- ★ Dress himself and get ready for school.
- ★ Take a class or learn a skill, such as playing the piano.

Besides the things he wants to do, he can also help out with the house. He can:

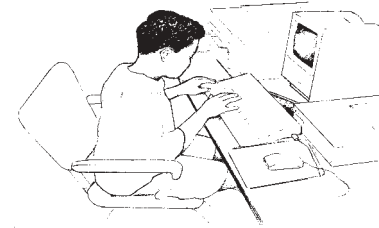
- ★ Help with household chores.
- ★ Clean up his room.
- ★ Clear and set the table.
- ★ Do the dishes.

Let him do things himself unless you're certain they are not safe. Even if it takes longer, it is good for him to do them.

Help your child plan what she needs to do. Young children often need more help than older children. For example, when you ask a 6 year-old to clean up her room, explain what you mean. Tell her to:

- ★ Put toys in the chest.
- ★ Put clothes in the hamper.
- ★ Put the covers up on the bed.

By the time they are older, they should know what it means to "clean-up their room".



Doing things for themselves

If the child doesn't ask to do things by himself, you may need to push a little. People often find it hard to push a child who has an illness. They feel guilty or afraid. Don't let the child's illness get in the way of helping them grow up. It's OK to let them fail sometimes. That is part of how we all learn what we can do.

No matter what, don't do everything for the child. When she does things for herself, she will feel good about it.

You are not the only one who may try to protect the child too much. Family members, teachers and friends may feel that she needs special care. Have them focus on what the child can do, not what she can't do. The child doesn't need their "help". She needs their support for growing up.



Sickle Cell Summer Camp

Summer camp is always filled with outdoor fun, new friends, singing, swimming, story-times and games. At sickle cell summer camp, counselors know how to help children with the disease do as much as they can, without hurting themselves. The staff is aware of the special needs of children with sickle cell disease and can handle any problems that may arise.

Sickle cell summer camp provides a safe and fun setting for your child to gain confidence and self-esteem. Spending time away from parents with other children her/his own age will help the child be more independent.

Ask the doctor or local sickle cell group about where you can get information about the nearest camp.